

103D CONGRESS
1ST SESSION

H. R. 1296

To provide surveillance, research, and services aimed at prevention of birth defects.

IN THE HOUSE OF REPRESENTATIVES

MARCH 10, 1993

Mr. ORTIZ (for himself, Mr. SLATTERY, Mr. WILSON, Mr. EVANS, Mr. PASTOR, Mr. GONZALEZ, Mr. TOWNS, Mr. McDERMOTT, Mr. COLEMAN, Mr. FILNER, Mr. TEJEDA, Ms. PELOSI, Mr. ROMERO-BARCELÓ, Mr. DE LA GARZA, Mr. GUTIERREZ, Mr. BLACKWELL, Mr. PICKLE, Mr. FROST, Mr. DIXON, Mr. GENE GREEN of Texas, Mr. LIPINSKI, Mr. KREIDLER, Mr. TORRES, and Mr. SERRANO) introduced the following bill; which was referred to the Committee on Energy and Commerce

AUGUST 2, 1993

Additional sponsors: Mr. HALL of Texas, Mrs. THURMAN, Mr. BROWN of Ohio, Miss COLLINS of Michigan, Mr. GORDON, Mrs. CLAYTON, Mr. CRAMER, Mr. HALL of Ohio, Mr. ROSE, Mr. HUGHES, Mr. MFUME, Mrs. SCHROEDER, Mrs. LLOYD, Mrs. MORELLA, Mr. UPTON, Mr. LAUGHLIN, Mr. BRYANT, Mr. OWENS, Mr. ACKERMAN, Mr. SARPALIUS, Mr. LEVIN, Mr. EDWARDS of Texas, Mr. DOOLEY, Mr. INSLEE, Ms. EDDIE BERNICE JOHNSON of Texas, Mr. PRICE of North Carolina, Mr. WYNN, Mr. RICHARDSON, Mr. MENENDEZ, Mr. MARKEY, Mr. WASHINGTON, Mr. ROWLAND, and Mr. DELLUMS

A BILL

To provide surveillance, research, and services aimed at prevention of birth defects.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE; FINDINGS.**

2 (a) SHORT TITLE.—This Act may be cited as the
3 “Birth Defects Prevention Act of 1993”.

4 (b) FINDINGS.—The Congress makes the following
5 findings:

6 (1) Birth defects are the leading cause of infant
7 mortality, directly responsible for one out of every
8 five infant deaths.

9 (2) Thousands of the 250,000 infants born with
10 a birth defect annually face a lifetime of chronic dis-
11 ability and illness.

12 (3) Birth defects threaten the lives of infants of
13 all racial and ethnic backgrounds. However, some
14 conditions pose excess risks for certain populations.
15 For example, compared to all infants born in the
16 United States, Hispanic-American infants are more
17 likely to be born with anencephaly spina bifida and
18 other neural tube defects and African-American in-
19 fants are more likely to be born with sickle-cell
20 anemia.

21 (4) Birth defects can be caused by exposure to
22 environmental hazards, adverse health conditions
23 during pregnancy, or genetic mutations. Prevention
24 efforts are slowed by lack of information about the
25 number and causes of birth defects. Outbreaks of
26 birth defects may go undetected because surveillance

1 and research efforts are underdeveloped and poorly
2 coordinated.

3 **SEC. 2. BIRTH DEFECTS PREVENTION AND RESEARCH PRO-**
4 **GRAM.**

5 Part B of title III of the Public Health Service Act
6 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
7 tion 317A the following new section:

8 “BIRTH DEFECTS PREVENTION AND RESEARCH
9 PROGRAMS

10 “SEC. 317B. (a) NATIONAL BIRTH DEFECTS SUR-
11 VEILLANCE PROGRAM.—The Secretary, acting through
12 the Director of the Centers for Disease Control, may
13 award grants to, enter into cooperative agreements with,
14 or provide direct technical assistance in lieu of cash to
15 States, State health authorities, or health agencies of po-
16 litical subdivisions of a State for collection, analysis, and
17 reporting of birth defects statistics from birth certificates,
18 infant death certificates, hospital records, or other sources
19 and to collect and disaggregate such statistics by gender
20 and racial and ethnic group.

21 “(b) CENTERS FOR EXCELLENCE FOR BIRTH DE-
22 FECTS PREVENTION RESEARCH.—

23 “(1) IN GENERAL.—The Secretary shall estab-
24 lish at least five regional birth defects monitoring
25 and research programs for the purpose of collecting
26 and analyzing information on the number, incidence,

1 correlates, and causes of birth defects, to include in-
2 formation regarding gender and different racial and
3 ethnic groups, including Hispanics, non-Hispanic
4 whites, African Americans, Native Americans, and
5 Asian Americans.

6 “(2) AUTHORITY FOR AWARDS.—For purposes
7 of paragraph (1), the Secretary, acting through the
8 Director of the Centers for Disease Control, may
9 award grants or enter into cooperative agreements
10 with State departments of health, universities, or
11 other private, nonprofit entities engaged in research
12 to enable such entities to serve as Centers of Excel-
13 lence for Birth Defects Prevention Research.

14 “(3) APPLICATION.—To be eligible for grants
15 or cooperative agreements under paragraph (2), the
16 entity shall prepare and submit to the Secretary an
17 application at such time, in such manner and con-
18 taining such information as the Secretary may pre-
19 scribe, including assurances that—

20 “(A) the program will collect, analyze, and
21 report birth defects data according to guidelines
22 prescribed by the Director of the Centers for
23 Disease Control;

1 “(B) the program will coordinate States
2 birth defects surveillance and prevention efforts
3 within a region;

4 “(C) education, training, and clinical skills
5 improvement for health professionals aimed at
6 the prevention and control of birth defects will
7 be included in the program activities;

8 “(D) development and evaluation of birth
9 defects prevention strategies will be included in
10 the program activities, as appropriate; and

11 “(E) the program funds will not be used to
12 supplant or duplicate State efforts.

13 “(4) CENTERS TO FOCUS ON RACIAL AND ETH-
14 NIC DISPARITIES IN BIRTH DEFECTS.—One of the
15 Centers of Excellence shall focus on birth defects
16 among ethnic minorities, and shall be located in a
17 standard metropolitan statistical area that has over
18 a 60 percent ethnic minority population, is federally
19 designated as a health professional shortage area,
20 and has an incidence of one or more birth defects
21 more than four times the national average.

22 “(c) CLEARINGHOUSE.—The Centers for Disease
23 Control shall serve as the coordinating agency for birth
24 defects prevention activities through establishment of a
25 clearinghouse for the collection and storage of data and

1 generated from birth defects monitoring programs devel-
2 oped under subsections (a) and (b). Functions of such
3 clearinghouse shall include facilitating the coordination of
4 research and policy development to prevent birth defects.
5 The clearinghouse shall disaggregate data by gender and
6 by racial and ethnic groups, the major Hispanic
7 subgroups, non-Hispanic whites, African Americans, Na-
8 tive Americans, and Asian Americans.

9 “(d) PREVENTION STRATEGIES.—The Secretary, act-
10 ing through the Director of the Centers for Disease Con-
11 trol, shall award grants to or enter into cooperative agree-
12 ments with State departments of health, universities, or
13 other private, or nonprofit entities to enable such entities
14 to develop, evaluate and implement prevention strategies
15 designed to reduce the incidence and effects or birth de-
16 fects including—

17 “(1) demonstration projects for the prevention
18 of birth defects, including—

19 “(A) at least one project aimed at enhanc-
20 ing prevention services in a ‘high-risk area’ that
21 has a proportion of birth to minority women
22 above the national average, is federally des-
23 ignated as a health professional shortage area,
24 and has a high incidence of one or more birth
25 defects; and

1 “(B) at least one outcome research project
2 to study the effectiveness of infant interventions
3 aimed at amelioration of birth defects; and

4 “(2) public information and education programs
5 for the prevention of birth defects, including but not
6 limited to programs aimed at prevention of alcohol
7 and illicit drug use during pregnancy and promotion
8 of use of folic acid vitamin supplements for women
9 of childbearing age in a manner which is sensitive to
10 the cultural and linguistic context of a given commu-
11 nity.

12 “(e) ADVISORY COMMITTEE.—

13 “(1) ESTABLISHMENT OF COMMITTEE.—The
14 Secretary shall establish an Advisory Committee for
15 Birth Defects Prevention (in this subsection referred
16 to as the ‘Committee’). The Committee shall provide
17 advice and recommendations on prevention and ame-
18 lioration of birth defects to the Secretary and the
19 Director of the Centers for Disease Control.

20 “(2) FUNCTIONS.—With respect to birth de-
21 fects prevention, the Committee shall—

22 “(A) make recommendations regarding
23 prevention research and intervention priorities;

1 “(B) study and recommend ways to pre-
2 vent birth defects, with emphasis on emerging
3 technologies;

4 “(C) identify annually the important areas
5 of government and nongovernment cooperation
6 needed to implement prevention strategies;

7 “(D) identify research and prevention
8 strategies which would be successful in address-
9 ing birth defects disparities among the major
10 Hispanic subgroups, non-Hispanic whites, Afri-
11 can Americans, Native Americans, and Asian
12 Americans; and

13 “(E) review and recommend policies and
14 guidance related to birth defects research and
15 prevention.

16 “(3) COMPOSITION.—The Committee shall be
17 composed of 15 members appointed by the Sec-
18 retary, including—

19 “(A) four health professionals, who are not
20 employees of the United States, who have ex-
21 pertise in issues related to prevention of or care
22 for children with birth defects;

23 “(B) two representatives from health pro-
24 fessional associations;

1 “(C) four representatives from voluntary
2 health agencies concerned with conditions lead-
3 ing to birth defects or childhood disability;

4 “(D) five members of the general public, of
5 whom at least three shall be parents of children
6 with birth defects or persons having birth de-
7 fects; and

8 “(E) representatives of the Public Health
9 Service agencies involved in birth defects re-
10 search and prevention programs and represent-
11 atives or other appropriate Federal agencies, in-
12 cluding but not limited to the Department of
13 Education and the Environmental Protection
14 Agency, shall be appointed as ex officio, liaison
15 members for purposes of informing the Com-
16 mittee regarding Federal agency policies and
17 practices;

18 “(4) STRUCTURE.—

19 “(A) TERM OF OFFICE.—Appointed mem-
20 bers of the Committee shall be appointed for a
21 term of office of 3 years, except that of the
22 members first appointed, 5 shall be appointed
23 for a term of 1 year, 5 shall be appointed for
24 a term of 2 years, and 5 shall be appointed for

1 a term of 3 years, as determined by the Sec-
2 retary.

3 “(B) MEETINGS.—The Committee shall
4 meet not less than three times per year and at
5 the call of the chair.

6 “(C) COMPENSATION.—Members of the
7 Committee who are employees of the Federal
8 Government shall serve without compensation.
9 Members of the Committee who are not employ-
10 ees of the Federal Government shall be com-
11 pensated at a rate not to exceed the daily equiv-
12 alent of the rate in effects for grade GS-18.

13 “(f) REPORT.—The Secretary shall prepare and sub-
14 mit to the Committee on Energy and Commerce of the
15 House of Representatives and the Committee on Labor
16 and Human Resources of the Senate a biennial report re-
17 garding the incidence of birth defects, the contribution of
18 birth defects to infant mortality, the outcome of implemen-
19 tation of prevention strategies, and identified needs for re-
20 search and policy development to include information re-
21 garding the various racial and ethnic groups, including
22 Hispanic, non-Hispanic whites, African Americans, Native
23 Americans, and Asian Americans.

24 “(g) AUTHORIZATION OF APPROPRIATIONS.—

1 “(1) For the purpose of carrying out sub-
2 sections (a), (b), and (c), there are authorized to be
3 appropriated \$15,000,000 for fiscal year 1994,
4 \$20,000,000 for fiscal year 1995, and such sums as
5 may be necessary for each of the fiscal years 1996
6 and 1997.

7 “(2) For the purpose of carrying out subsection
8 (d), there are authorized to be appropriated
9 \$15,000,000 for fiscal year 1994, \$20,000,000 for
10 fiscal year 1995, and such sums as may be nec-
11 essary for each of the fiscal years 1996 and 1997.

12 “(3) For the purpose of carrying out sub-
13 sections (e) and (f), there are authorized to be ap-
14 propriated \$2,000,000 for each of the fiscal years
15 1994 through 1997.”.

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